



January 22, 2014

Re: Draft 1115 Waiver Application

Dear Colleague:

Thank you for the opportunity to comment on the Draft 1115 waiver for Illinois Medicaid. The Cystic Fibrosis Foundation supports the transformation of the health care delivery system into a patient-centered system that encourages comprehensive, quality care. However, we recommend that in any reform effort, special attention be paid to the needs of individuals with rare genetic diseases who require multi-disciplinary specialty care. We encourage reliance on certain existing integrated delivery systems, such as accredited cystic fibrosis care centers, as models for system transformation and urge care in implementing a risk-based system for those with intensive health care needs.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 1,062 people in Illinois. CF causes the body to produce thick, sticky mucus that clogs the lungs and can lead to serious and life-threatening infections and irreversible lung damage. Through the development of cutting edge new therapies and a national network of CF care centers that provide care of consistently high quality, people with CF are living into their 30s and beyond. The CF Foundation has funded, coordinated, and led CF research and therapeutic development efforts and has also fostered and coordinated the national network of CF care centers.

The CF care center network is guided by many of the principles that the concept paper identifies as vital components of delivery system transformation, including team-based care practices, the sharing of performance reports with health professionals to foster quality improvement, and ensuring the delivery of the right care at the right time in the most appropriate setting. This system should be protected and sustained during the overall transformation of Medicaid.

Integrated Delivery Systems

The concept paper encourages the transformation of the health care delivery system through care coordination entities, or CCEs, and accountable care entities, or ACEs. We agree that there is significant promise in utilizing CCEs to improve the care to certain well-defined subpopulations of patients. The concept paper suggests that the CCEs should be primary care organizations, or at least will have primary care providers in a leadership role. We urge reconsideration of this standard, or at least flexibility regarding the design of CCEs for medically complex populations. For example, in the case of CF, the state would be well-advised to utilize the existing multidisciplinary care networks that are primarily specialty care networks. We believe that

integrated networks of specialists who care for those with CF have already achieved the high standards of quality and efficiency that the state seeks through the CCEs and should be part of the waiver program. In addition, we do not believe that strict limits on the number of providers who may be included in the CCEs are in the best interest of CF patients and others with serious and life-threatening illnesses who may already be treated by disease experts through specialty networks. These patients, who face a lifetime of daily care for their disease, have often developed relationships with their care teams that should not be interrupted, lest there be a decline in the overall quality of the care that they receive. Strict limits in provider networks, or CCEs, might jeopardize this continuity of care.

We also urge caution in the imposition of risk-sharing for multidisciplinary networks of specialists caring for those with CF and other serious and life-threatening illnesses. The pace of discovery regarding CF treatments is rapid, resulting in the introduction of important new treatments into the standard of care. It is this cycle of research and development that has contributed significantly to enhancements in life expectancy for those with CF. Any system transformation that is risk-based must include patient protections to ensure that there are not inappropriate barriers to new, life-saving treatments.

We also recommend that the performance of CCEs be evaluated according to clinical guidelines and standards and quality standards. These standards are necessary to ensure that the right treatment is provided at the right time and that the transformation of the system does not result in underutilization that threatens access to quality, specialized care for this small but complex disease population.

Please consider us a resource moving forward.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', with a stylized, cursive script.

Mary B. Dwight
Vice President for Government Affairs